

Rare Is Everywhere

Awareness, Advocacy, and
Sharing Your Story

Includes
Wiedemann-
Steiner
Syndrome
(KMT2A)

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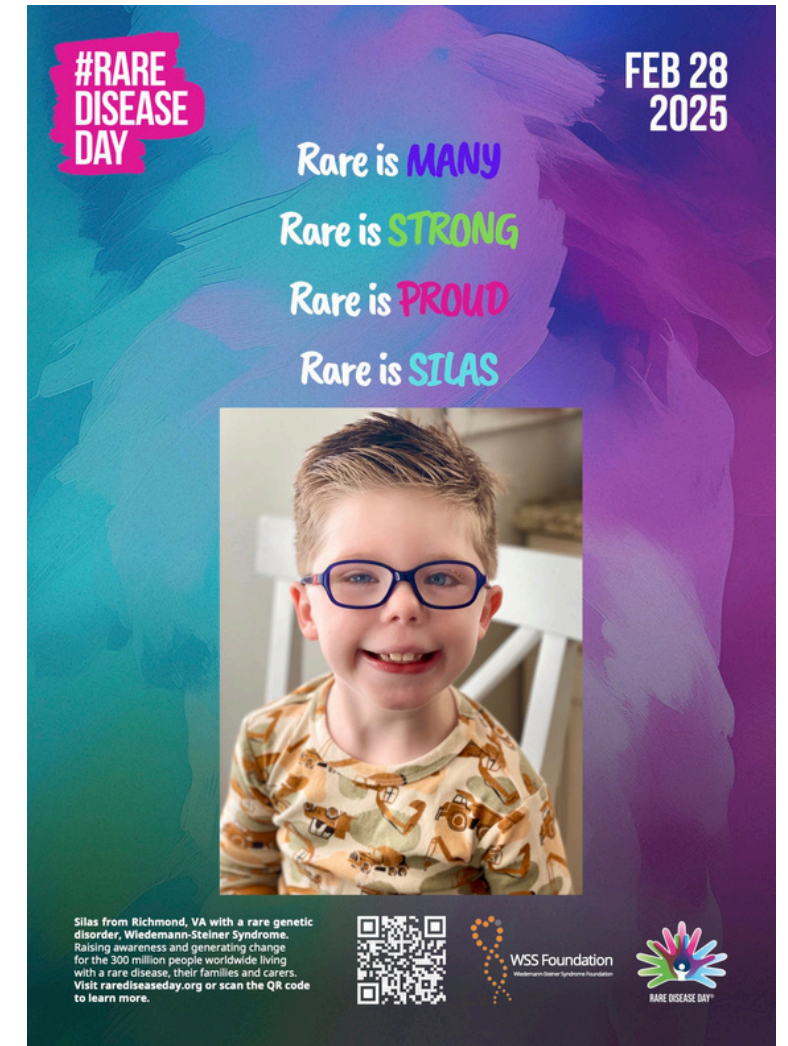


Objectives

- To raise public awareness of an issue (rare diseases/disorders) by expanding my personal interactions with others in the community and implementing an awareness and advocacy event on Rare Disease Day, which is the last day of every February - the rarest day of the year
- To utilize the leadership skills and knowledge I have gained as a LEND family discipline trainee to empower and educate others, foster empathy and connection by sharing my story, experiences, and the resources I have learned about with others in the community
- To inspire on-going advocacy and community engagement to help create change through personal story sharing - a powerful tool leaders can utilize to promote social change
- To develop a brief guide on tips for sharing your story

Rare Disease Day Facts

- 1 in 10 Americans are living with a rare disease/disorder and half are children
- Rare is one that affects fewer than 200,000 people
- Impacts more than 300 million people worldwide
- Over 7,000 identified rare diseases
- Awareness leads to...
 - increase of community support
 - increase of research and development
 - better diagnosis, treatment, and care
 - a crucial step before engagement
 - giving a voice to those who may not be able to advocate for themselves



Rare Disease Day Awareness and Advocacy

- 'Rare Ride' CycleBar event implemented on Rare Disease Day, February 28, 2025
 - "show your stripes, share your voice, spread community awareness"



Why I Raise Awareness: Meet Silas

- Born with **Wiedemann-Steiner Syndrome (WSS)**
 - affects about 1 in 25,000-40,000 people worldwide (exact estimate unknown)
 - most cases are spontaneous mutations, or '*de novo*' (not inherited from parents)
 - symptoms can include developmental delays, neurodevelopmental disorders; intellectual disability, communication disorders, ASD, ADHD, etc., neurological, muscular, & skeletal abnormalities, growth restriction, excessive hair growth, distinctive facial features, frequent infections, gastrointestinal & cardiac abnormalities, among various others.



Just after WSS diagnosis, age 3.5

Zebra drawing by little brother, Levi

Rare Disease Day, February 28

Efforts and Outcomes of Sharing Your Story

- Storytelling is one of the most valuable and impactful skills a leader can have, such as:
 - advocating for greater inclusion and accessibility through sharing your story
 - building empathy, authenticity, and connection of support systems
 - addressing societal and systemic barriers, and inequities through sharing challenges faced and obstacles overcome
 - impacting policy and systems change

Why the Zebra?

- The zebra is the official mascot of rare diseases. There is an old saying used in medical school, "When you hear hoofbeats, think of horses, not zebras." This encouraged medical students to consider common conditions rather than rare ones. But now we know that 1 in 10 people are actually a zebra, which is why the zebra's unique and distinctive stripes have become a symbol to represent the rare community.



References

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